DOCUMENT RESUME

ED 096 786 EC 062 945

TITLE	MR 73: The Goal Is Freedom. Annual Report of the President's Committee on Mental Retardation.
INSTITUTION	President's Committee on Mental Retardation, Washington, D.C.
REPORT NO	DHEW-OHD-74-21001
PUB DATE	[74]
NOTE	35p.
EDRS PRICE	MF-$0.75 HC-$[illegible].85 PLUS POSTAGE
DESCRIPTORS	*Annual Reports; Behavior Change; Case Studies; Educational Programs; Employment Potential; *Exceptional Child Services; Goal Orientation; Group Living; Identification; Institutions; Intervention; Medical Research; *Mentally Handicapped; Prenatal Influences; Prevention; Program Evaluation; Public Relations
IDENTIFIERS	*Presidents Committee on Mental Retardation

ABSTRACT

Presented is the seventh annual report of the President's Committee on Mental Retardation (PCMR). Stressed are the members' beliefs in the capability of continuing development by mentally retarded people, in early detection and correction of handicaps, and in prevention through prenatal and neonatal biomedical intervention. Emphasized is the necessity for client-centered programs, with evaluation based on the amount of client improvement as a result of service. Described in the first section of the report are steps toward growing functional independence in educational, employment, and living situations by individual children and adults due to goal-oriented, personalized programs at such agencies as a children's center, a state school, a hospital for the multiply handicapped, a sheltered workshop, and a group home. The second section contains material related to prevention of mental retardation and early intervention programs, including discussions of prenatal research into the causes of handicapping conditions, methods of transporting high-risk infants, early childhood programs, and treatment to prevent long-term institutionalization. Covered in the third section are PCMR activities during 1973 with regard to areas such as legal rights, early childhood intervention, preparation for community living, housing and public information. The report includes photographs and the transcript of a group discussion by eight mentally retarded adolescents. (LH)

MR 73/ THE GOAL IS FREEDOM

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THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
Washington, D. C. 20201

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

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The President
The White House
Washington, D.C.

Dear Mr. President:

It is a pleasure to present to you the seventh annual report of the President's Committee on Mental Retardation, MR 73: The Goal Is Freedom.

This is a human document, concerning mentally retarded people who might have lived wasted lives had it not been for remedial action that enabled them to develop into contributing members of society, freed from those internal blocks that set them apart.

Some have been able to avoid dependency by early treatment. Some have been brought out of institutions into employment and community living. Others have been saved from retardation by preventive measures.

Both the prevention of mental retardation and the preparation of retarded people for community living are relevant to the goals you have set for the nation.

These achievements have been made possible by the application of modern behavioral and medical science in the prenatal, neonatal, and early childhood periods, in addition to the concept of continuous development for all retarded persons, no matter what the age.

Evaluation of programs can now be based on specific data, with records showing individual progress along a continuum of objectives toward a stated goal for each person. The criterion for evaluation has changed from whether or not the client is being served to how much improvement the client has shown as a result of the service.

We commend these advances to your attention. We ask your support in helping to bring these services to all retarded individuals and to all those at risk of being born retarded.

Faithfully yours,

Caspar W. Weinberger
Chairman

(Mrs.) N. Lorraine Beebe
Vice Chairman

INTRODUCTION

This report is not about "the mentally retarded."

It is about a little boy who failed to thrive because he had been abandoned; a young girl suffering from the emotional effects of 16 years in a State school; a group of "crib cases" who were helped to function as human beings and given their identities; a young woman emerging as an adult after 26 years as a child.

The primary diagnosis for all of these people was mental retardation. The primary problem for each, however, was fear, or social inadequacy, or physical limitations. These internal, personal barriers to freedom were more responsible for keeping them from living meaningful lives than their IQs.

When they were recognized as individuals, each different from the other, each with potential for further development, they were given help based on individualized assessment of their actual needs.

As a result, they did develop, and are still developing as persons, step by step, toward realistic goals.

The expectation of continuing development toward objectives and goals, set on the basis of individual assessments, and measurable on achievement scales, promises to become the guiding principle in the mental retardation field.

Consequently, planning for services is shifting from a program-centered approach to a client-centered one. The criterion for evaluating programs is no longer: How many clients are being served? It is becoming: Are the clients developing as a result of this program?

The President's Committee on Mental Retardation therefore has chosen to base the first section of this report on individual children and adults who have grown and developed as a result of this goal-oriented, personalized concept. Large-scale, long-term results are not yet available, since application of the concept is relatively new.

The report is also concerned with other kinds of programs that can aid in avoiding dependency and promoting optimum development. The main emphasis here is on prevention of the problem. The second section consequently contains material related to research on prevention and early intervention. It is based on presentations given at a four-State Forum held by PCMR in Kansas City, Missouri in the Fall of 1973.

Areas covered include prenatal research into the causes of handicapping conditions, the oldest and at the same time the newest method of transporting a high-risk infant, early childhood programs for handicapped children, and treatment to prevent long-term institutionalization.

One of the methods of communicating such advances is this annual report from the President's Committee on Mental Retardation to the President and to the American people.

Other activities conducted by the Committee in 1973—in the field of legal rights, early childhood intervention, preparation for community living, housing, public information, among numerous others—are covered in the report's third section. All are designed to promote progress in preventive measures, or to create a climate that will enable individuals who are retarded to live as normal a life as possible.

Taken all together, the underlying philosophy of the entire report was expressed over 100 years ago by Thomas Carlyle:

> *"Let each become all that he was created capable of being; expand, if possible, to his full growth, and show himself at length in his own shape and stature, be these what they may."*

DHEW Publication No. (OHD) 74-21001

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bears witness to the Committee's beliefs that:

- Mentally retarded people are capable of continuing development.
- Corrective measures introduced in early childhood can reduce the severity of the handicap and sometimes reverse its course.
- Prenatal and neonatal biomedical intervention can prevent many forms of mental retardation and related handicaps.

STEP BY STEP TOWARD FREEDOM

"We will let him show us what he can do."

He was like a frightened deer when he arrived at the children's center. A small, wild creature, clawing, biting, kicking everyone within reach, including himself.

At five, he spoke only a few words. Prolonged screams were his principal means of protesting captivity.

Mentally ill?

Mentally retarded?

His last psychological evaluation, when he was four, tentatively gave him an IQ of about 30.

"Forget the diagnosis," said the center's director. "He is a frightened child. We will work with him and see what happens. We will let him show us what he can do. And then we will work with him some more."

Bryan is seven now, a sociable, outgoing little boy who is the pride of his foster family. Aggressiveness has turned into leadership; he often plays teacher to his class.

Soon he will graduate from the center's program to a special education class in public school. Later, he may be able to move into a regular class. No one knows yet. After all, he has traveled so far in the last few years. . . .

At least it appears that he is headed for a self-sufficient life. Two years ago he was headed for a lifetime in an institution.

Bryan is one of an increasing number of retarded individuals who are being helped to develop toward personal freedom and functional independence through intensive, individualized programs that are oriented toward practical goals.

Rather than being catch-all programs planned on the basis of IQ level, the newer programs are designed to answer unique needs, and to remove those personal, inner barriers that tend to set mentally retarded persons apart from the rest of society.

In many cases, retarded mental development is not the major problem. The main factors blocking individual progress may be uncontrolled emotions, or negative self-image, or entrenched negative habits that are reinforced with repetition, or physical handicaps. These "side effects" are often more inhibiting to development than mental retardation itself.

For Bryan, the road to freedom has been filled with barriers, both external and internal, from the day he was born.

He was premature, and weighed just a little over two pounds. So he stayed in the hospital for the first five months. There, at least, he survived, though just barely.

From then on, because his mother was unable to care for him, and because of his "failure to thrive," he was in and out of hospitals for five years. When he was out, he was in receiving homes except for a brief time after his first birthday, when he went home.

A social worker found him there, alone, abandoned, eating his own feces.

Each receiving home, each hospital did for him what their limited resources allowed. He wasn't neglected. The hospitals treated him for his physical ills, and one started him on a sensory stimulation program, which began to bring him out of his emotional prison.

It wasn't that no one cared. They cared deeply, wrote long, agonized descriptions of his behavior and his needs—"but his needs reach beyond this program. . . ."

From tests made when he was four, he appeared to be functioning at a little over a one-year-old level, IQ 30+, although the psychologist noted that his bizarre behavior and deprived background made meaningful results almost impossible.

He screamed or cried constantly, rocking back and forth in bed or on the floor. He plucked at his skin until it was raw. No speech. No relationship to people. A little boy tuned out, captive of his own inner world of terror.

When he was referred to the children's center they ignored the test results.

But there was no way to ignore Bryan.

During the first few months there he would tear into the director's office whenever he got the chance, destroying papers, pictures, books,

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anything he could reach. He was five then.

Less than six months later he was still running into his office, but now for a daily hug, and a little talk.

By that time, he was quite a little mimic with his new-found method of communication: Speech. The staff often wondered if he would pick up the director's Hungarian cadences. He didn't.

The specifics of treatment at the center are carefully and individually prescribed, but, more important, the attitudes of the staff and administrators are shaped by the philosophy expressed in every act: Each individual is precious and each is capable of continuing development.

When a child is deprived of normal stimulation, he often begins to stimulate himself. This can become destructive in certain children who may injure themselves severly by head-banging, biting, or other kinds of self-mutilation. So the staff attempts to substitute the negative acts with positive ones, the destructive stimulation with constructive stimulation.

"Early age is the best time to get them," says the director. "When they come here they are already failures, rejected by the system, rejected by themselves—sometimes by the time they are five years old.

"Here we try to reinforce success. Success is sweet, and it's fun to succeed."

Bryan had no tolerance for failure. At first, during the behavior shaping,

there were very few successes to reinforce. They came more frequently as he began to respond to the unfamiliar experience of having one person's fulltime attention all day in the beginning of his therapy.

Then he moved up to groups of two, three, then a class of five or six. The temper tantrums, the screaming, the rocking, and finger plucking at his skin gradually subsided.

Eventually—it took many months—he decided it was more fun to do what the class was doing than to go his own way. He was discovering that cooperation has its rewards. He began to choose to cooperate.

Slowly, the academic program started. It took weeks of training for him to be able to sit still on a chair and observe the teacher for even the briefest length of time, one of the first of the "educational survival techniques" the children are taught.

When he mastered this art, the first objective had been reached toward the goal of learning how to learn.

The check marks on his achievement chart were moving further over from the "Never" column, through the "Sometimes," the "Usually," and more into the "Always."

Bryan was ready now to learn how to read.

And so on up the ladder of learning and behavior. He may not make it all the way to the top. The scars of his formative years run deep. But he is still climbing.

Even though the program at the children's center is individualized and highly personal, it is systematized and structured, the program director, a psychologist, explains. "We structure the situation, and build the environment around the child in order to get constructive change."

Each instructional program is broken down into specific units, each unit containing both a detailed procedure and a clearly defined behavior goal.

The teacher then can record baseline behaviors for each of the children studying the unit. Thus, research and services are joined. The children's progress can be measured, and also the relative effectiveness of each of the components can be analyzed.

After behavior is modified to the extent that the child is able to exert inner controls, the staff begins to introduce academic learning.

One of the goals is to give the child the skills needed to survive in the educational system. Another is to promote inner motivation that will carry him through on his own.

"These flowers must bloom in the cold, outside world, not just in this hothouse."

The staff tries to involve the parents as much as possible, although only about half are able to take part. Some are employed by the center.

IQs are seldom mentioned there. And although there are records containing diagnoses, test scores, performance assessment and other relevant information, they are used only as aids to individual program planning and assessment—never as a means of identifying the person. They are kept confidential. When a child goes from the program into a regular classroom in public school—as many do—no labeling goes with him. "He's then just a nice kid in school," says the director. "Some administrators love to call children by their diagnosis. We don't give them the chance. If there's any trouble, his mother knows where she can come for help."

The center's basic goals are best described by the director:

"When we get the children at four or five or older, the cycle of behavior, of performance, is turning one way—negative, negative.

"A temper tantrum is negative fun.

"Then we give them a taste of something that's more fun. Being hugged, patted, smiled at, cuddled for doing the right things. They soon find that, yes, that is more fun than biting and screeching.

"Pretty soon the cycle begins to reverse. Slowly. We all—all of us—push, push toward the positive. Replace all the negatives with positives. You take away something bad, you have to put something good in its place. Reach an objective, put the next one higher.

"Now we introduce a little academic learning—a number, a letter.

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Just a little bite at first. Once they taste the joys of learning, the learning itself becomes reinforcing.

"We give a little more push. Positive, always toward the positive. The cycle is beginning to turn more quickly now.

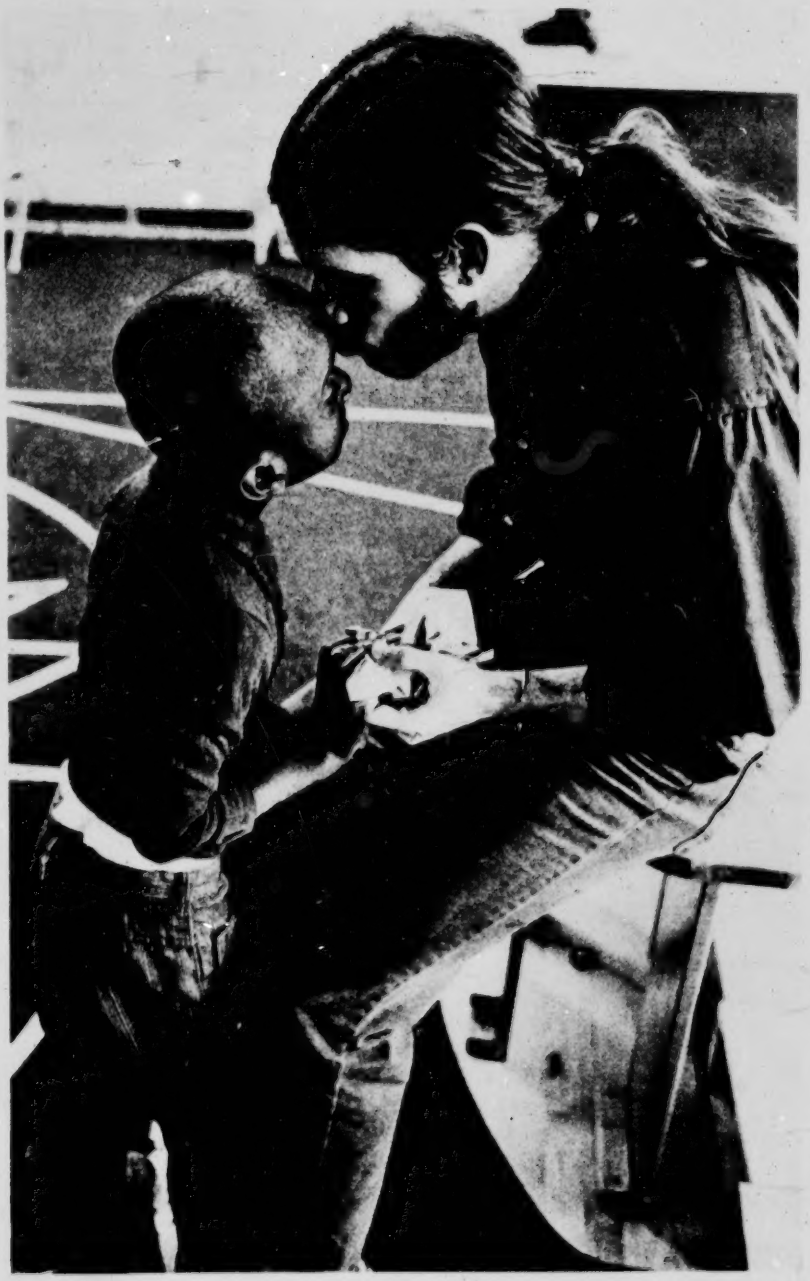
"Then all of a sudden something clicks.

"And you know that the child is beginning to push that inner wheel himself. That is the wonderful time.

"When the wheel inside is turning all by itself, then he is ready. We are done. And, God willing, then he has gained enough inner direction, motivation, momentum to carry him through. When someone on the outside yells at him, he can take it, because there is still the inner strength.

"And the wheel is still rolling—positive, positive."

Contained in those words are the "secrets" of helping handicapped individuals move toward a life of quality: Replacing negative with positive, emphasizing strengths, and setting objectives higher and higher—but still attainable—as each one is reached, toward the goal for each individual.



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"You never know how far a person can go, once she decides she wants to go there."

Last year Yolanda came out of the State school where she had been since she was two years old. She had stayed there for 16 years, becoming an institutionalized "retardate," fearful, docile, dull.

Her first attempt to hold a food services job and live in a group home failed, and she had to return to the institution.

The second venture into the world has succeeded.

She now has a job as a "Girl Friday" with a large corporation, where her puncture-proof good humor has made her an office favorite. Through her own initiative, she has parlayed the job from messenger to "office assistant," maintaining office supplies, and opening and closing the office each day, since she is on the job earlier and later than anyone else.

In a project she calls her "insurance for the future," she is teaching herself to type.

Yolanda originally had requested the business course at the occupational center where she was trained for employment but, because of her past experience with failure, the staff preferred to start her in something less stressful. So she was prepared for food services instead.

"That just proves," the center's program director commented, "you never know how far a person can go once she decides she wants to go there."

Only a few of her fellow workers know that she used to be labeled retarded.

Yolanda failed in her first job not because she was retarded, but because she wasn't making the most of her abilities. When she found what she did best—working in an office—she bloomed. And she is still progressing.

She may not ever become the president of the firm, but she'll never again stagnate in an institution. Even in economic terms, that was a poor investment. She was costing the taxpayers about $6,500 yearly. She's now proudly paying taxes and contributing in many other ways to society and the nation.

The first experiment in group living failed because Yolanda prefers living alone. Also perhaps because she was not so mature then as she is now. Counseling and personal adjustment courses at the training center have raised her level of maturity. And she's grown out of the rebellious adolescent stage that retarded as well as most other young people go through.

She's enjoying living by herself in her own apartment—a prime example of the necessity for offering a choice of life-styles geared to the individual.

Candidates for community placement, such as Yolanda, are bussed in daily to the training center from nearby residential State schools.

Because most are in their teens, the center provides a high school atmosphere, and offers sports and recreation in addition to the classes. Most of the classes are concerned with personal adjustments and job training, but there is academic work also, fitted to job requirements.

Initial concentration is on personal adjustment: Developing good work habits; eliminating the internal obstacles to progress; telling time, and developing a time sense; social and emotional adjustment.

There is a great deal of role playing and simulation of social and work situations.

"We work to get them to a level of maturity that will enable them to live in a group home or half-way house or independently, and to work successfully on a job," says the training center's director.

After much counseling and evaluation of their skills, they then start on actual job training for food services, maintenance or business work. For two to three months, six hours a day, they work in a simulated job situation.

Around this time, a couple of months before job placement, they move into a half-way house. "The program is set up and timed so that there will be as few simultaneous traumatic experiences as possible," a counselor says. "Starting a job and moving into a community at the same time is too much, especially if there are transportation problems."

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The length of preparation varies for each individual, depending on whether he or she meets the criteria of the center, and whether goals have been met.

When the staff feels a client is ready, and has met the criteria, the placement officer goes into the community and seeks the jobs to suit individual talents. There are several sessions with potential supervisors, counseling with them as well as with the clients.

Sometimes the placement officer goes with the client for the initial job interview. In some instances, this is more for the benefit of the supervisor of the job than for the employee.

Before the job starts, there is transportation training. Transportation can be one of the largest external obstacles encountered. But accessibility of the job to the living situation is always a major consideration, before job placement.

There is frequent follow-up for the first few months, then periodic checks for the first year or so.

The alumni keep in touch, many returning once a month for a social evening at the center.

"We don't deal in IQs," the director says. "It doesn't even make any difference whether our students are supposed to be 'educable' or 'trainable' or whatever label someone has slapped on them. All that's important to us is whether they can get and

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hold a job and take care of themselves either in sheltered or independent living after they leave here. The vast majority make it."

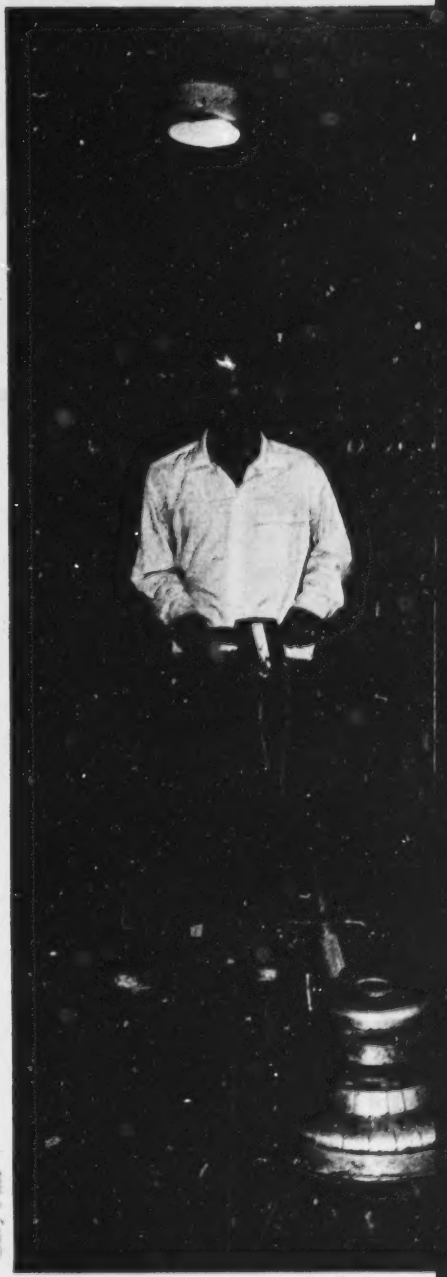
Throughout the classrooms, there are charts listing personal goals, arrived at after many sessions with the teacher and counselor.

Hanging beside the goals chart is a folder containing contracts made with themselves in cooperation with the teacher, a gentleman's agreement to achieve individual objectives.

"We don't change values here so much as we change ways of arriving at values," a teacher explains.

Yolanda has gone beyond fulfilling the terms of her personal contract. She's now setting her own goals and values, and they are higher than anyone thought she could reach.

NAME	GOALS *(Training)*	GOALS *(Personal Adjustment Training)*
Jimmy	Increase speed on assignment	Stop rolling eyes
Elrod	Stop complaining about work	Stop roving about class
Terry	Improve attitude	Lower voice level
Denise	Be punctual	Stop flirting



Gary Fine

Open-ended progress for each individual

The setting of goals and objectives for persons who are retarded is quickly gaining acceptance throughout the various planning levels, from individual programing, through to the federal level. The approach is realistic and geared to the human scale.

Some programs employ minutely detailed individualized assessment charts covering every facet of functioning. Others use a more informal procedure that requires a minimum of record-keeping. Measuring techniques also vary according to age, severity of handicap, and other factors.

In goal-oriented, individualized assessment and program planning systems—there are several varieties—there is, first, a one-to-one procedure to modify or strengthen behavior. This is done to enable the person to move up from whatever functional stage he is in to the next higher level. (Example: John now combs his hair unaided. The next objective may be brushing his teeth unaided.)

Each step is measurable on individualized assessment scales.

Group planning is possible for several persons in a given situation when they have reached a certain common objective. (Example: X number of bed-ridden clients have become ambulatory, or X number of clients living in a group home are moving into independent living.) The administrator can then chart realistically the broad functioning level of a group of individuals and can plan programs according to the next objective for these clients.

Requirements for staffing, equipment, budget planning, daily programming and all other aspects of program planning must be kept flexible to meet clients' current and actual needs.

Community, then State, and federal planning can also be based on cumulative data on functioning levels and resultant needs for clients in order that they can advance toward higher objectives.

Traditionally, in the program-centered approach, "the mentally retarded" within certain IQ ranges have been fitted into existing programs. Many of these kinds of programs are a dead-end for the retarded person.

Client-centered programs, goal-oriented and based on individual assessment charts, on the other hand, fit the program to the client. Resources can then be redirected toward actual needs.

For instance, clients in a day care center might be enabled to progress to a higher level of functioning if given intensified occupational training and socialization. Some may need orthopedic surgery, or dental work, in addition. Remedial programs of various kinds may be needed simultaneously.

Each step is a prelude to the next step in an open-ended progression.

Benefits of the intensive training toward an objective extend beyond the person served. Each person who learns to dress himself, for example, not only moves up from total dependency to semi-dependency, but also frees the person who has been dressing him for more constructive duties.

For people with severe handicaps, there are some fundamental objectives. With rare exceptions, being toilet trained and ambulatory are basic requirements for going to school or getting a job, or group living. Both are high priorities.

Once toilet training is accomplished, self-feeding may be possible. Then dressing unaided. Then. . . .?

Who knows how far the ladder of development reaches for each individual?

The ultimate goal is the achievement of maximum functional independence for each person within his capabilities.

Is such a goal feasible for even the most severely handicapped individuals who are incontinent and bedridden? The next pages indicate the answer.

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"Human beings inside. Handle with care!"

Viewed through the bars of the oversized crib, the diapered form lying there appears to be all arms and legs, frozen at grotesque angles.

Rows on rows of similar cribs holding similar faceless, nameless, sexless bodies line the walls.

In four wooden chairs drawn together, white-clad nurses' aides sit mutely folding mountains of diapers.

From the other end of the ward comes the only sound in the room, three community youth workers huddled together on a bench, giggling nervously.

The place reeks of a great variety of human waste.

This is one floor of a hospital for the "hopeless," the non-ambulatory, mentally retarded patient with multiple handicaps.

The linens, floors, walls are hospital clean. The patients, incontinent as they are, are as clean as they can be under the circumstances. They are fed as well as possible, considering their limited ability to chew and swallow. The staff-patient ratio is good.

In short, these patients are being served adequately. Requirements for

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this patient population needing nursing care are being met.

All other floors of the hospital are mirror images of this scene.

Except one.

The fifth floor, freshly painted in happy colors, is alive with murals and artistic designs by art students and community volunteers. A bright corridor leads to a door with a pronouncement attached: "CAUTION: Human beings inside. Handle with care!"

The door opens onto action and interaction, involvement, motion. A formerly nonambulatory boy of about eights walks up to greet the visitors. He plunges a hand into the pocket of his corduroy trousers with such vigor that they begin sliding to half mast, but he hikes them up. An aide in a blue pantsuit smiles at him as she rushes past to catch a frisbee released rather than thrown by a little girl seated on a mat. Near her on the same mat another aide is on his knees taking a blind child through the motions of tumbling.

A small group of children and adults doing art work at a table are so involved with one another that they are oblivious of the visitors. Some are staff, some residents. It is impossible to differentiate from the clothes they wear. There are no uniforms.

In a side room, two young children are asleep in cribs. But they are there because it is nap time, and they are taking their naps. Except for their shoes, they, like all the others on this floor, are fully clothed.

A few are in wheel chairs getting ready to be taken to the swimming pool. Everybody on this floor gets out at least twice a week.

The walls are in attractive pastels, decorated with residents' art work and posters proclaiming: "If you hear the music, join the singing." "No bird soars so high as he does with his own wings."

Basically, the needs as well as the physical and mental competencies of the *persons* living on the fifth floor are no different from those of the *patients* on all other floors. A few months ago, they, too, were lying motionless in rows of cribs.

The staff has not been increased for the fifth floor. When they weren't changing diapers or washing or feeding the patients, they used to sit and fold diapers like the staff on other floors. The staff is more in evidence on the fifth floor, but it is because on the other wards the staff tends to disappear for long periods during the day, to give in to the human urge to

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escape from a depressing scene, either down the corridors or to be absent for days at a time.

There is no appreciable increase in the cost of the fifth floor center of action over the wards of inaction below.

The changes are not due to a demonstration grant, and these persons on the road to mobility and selfhood will not slip back to being immobilized, faceless forms in a deadend hospital after a spurt of progress.

A total learning experience is taking place here for residents and staff alike. It has started on the fifth floor; it will gradually include the entire resident population. [Since this section of the report was written, the other floors have been included in the program with comparable results.]

The changes encompass the colors, the light, the furniture, the living space allotted each individual, the person-oriented design of that space, dynamically and effectively used. Words that shape attitudes are changed.

Hospital, ward, patient, retardate —all the inappropriate terms are being removed from signs as well as from vocabularies. Uniforms are disappearing, though roles remain clearly defined, and each knows that he has a responsibility in the total program plan—the laundry workers through to the director.

First and foremost, though, the change from immobility to forward motion on the developmental scale has been accomplished through the establishment of an ultimate goal: Liberation of the person.

"Can you help me get out?"

Age is no deterrent to further development and successful community living, even after nearly a lifetime of institutionalization, for some people.

"Can you help me get out?" The request came unexpectedly from a man raking up leaves on the institution grounds. He had not been on the list of residents to be interviewed by a county Association for Retarded Citizens group, there to interest residents in community living.

His hair was white, but his step firm, despite his 70 years. "I don't know how long I've been here," he told the group. "Long as I can recall."

He had heard from others about the program of training being offered, and decided that he wanted to be a part of it. In a very short time, he was accepted as a candidate. For the next month he went through the evaluation tests, including social adaptability. He passed with ease.

Now he is having the time of his life, living in a group home with some younger men.

He likes gardening and yard work. So the goal for him is a job as a yard man in an apartment complex for elderly persons, situated conveniently near the group home. Meanwhile, he is making the transition in a sheltered workshop run by the county ARC.

"This is really living," he says, as he draws up a chair for a checkers game with the other men after dinner.

"I'm staying here."

Some move toward independence and freedom of choice with ease. Some hold back, shackled by restraints too ingrained to overcome.

Miss Bessie's production rate outdistanced even the youngest worker in the sheltered workshop attached to the State home for retarded people. Every day she tried to better her record, and often did.

She was 56, a tiny, bird-like woman who had been in the institution since she could remember.

For the past 12 years she had been assembling components for hair driers, and she was proud of her work. "Nobody here can work any faster than me," she boasted, tilting back her head with mock arrogance.

A candidate for community living? She could make money with her skills.

"They better not try to get me out of here." She bristled at the thought of moving. "This is my home. I'm staying right here. And you'd better believe it."

When Miss Bessie was placed in the huge, isolated asylum, as they termed State schools in those days, it was thought to be the ideal life for retarded people.

Miss Bessie still thinks so. And for her, it is. Life "outside" would defeat her.

Out of the nest

Janice is 26. She has lived at home with her family all her life. The only time she was away from home overnight was when she spent a week at a camp for retarded adolescents.

For six years she has worked in a sheltered workshop doing routine jobs, and generally being pleasant, shy and quiet.

Perhaps that was her problem. She was so agreeable that she was no problem to anyone, so she was passed over when chances for advancement were being offered.

One day a teacher in the program had a long talk with her and found she liked the idea of working with people—"doing things to help them."

Evaluations showed she was capable of developing beyond her present job, and also seemed to be ready for moving out of the protected environment of living at home at the age of 26.

In this case, it was the parents who needed counseling more than their retarded daughter. After several sessions they began to see that she could grow more as a mature person if she were out of the nest. So she's now living in a group home and working a few hours a day giving lunch to children in a nearby nursery school. Gradually the time she spends there will expand.

She is making plans to move into her own apartment whenever she is financially capable of the move. A friend at the workshop will share the apartment.

In her spare time, Janice is now trying to organize a volunteer group to go on regular visits to a State school and provide friendship and recreation for the residents.

Long-range goals for Janice are being revised, with the sights raised, based on her short experience with new-found freedom.

"If I get a job will I have to leave here?"

The staff of the group home couldn't figure what was wrong with Harold. He was the most helpful and affable of the seven men who lived in the home. No one was more happy than he was to get out of the institution. But he resisted all efforts to place him in a job.

Finally, he confessed, "If I get a job will I have to leave here?"

Reassured that he would be involved in any decision concerning his life, and offered freedom of choice, he stopped worrying. A week later he had a job.

Home, for him, was the group home—at least for the present time.

The positive approach

The best hope for reaching the goal of freedom is prevention of the handicapping conditions that can rob individuals of their freedom and keep them dependent throughout their lives.

Across the nation, research is delving into the factors that promote healthy human development or those that disrupt development and result in damage that is often irreparable. The health and environment of both mother and father, even before conception occurs, is of importance, as is the genetic inheritance they will pass on to the child.

From conception on to completion of pregnancy, development and differentiation of tissues and organs, as well as growth (represented by increase in mass) are major determinants of the eventual intellectual and emotional functioning of the individual.

Though research has uncovered many causes of disorders beginning in the prenatal period, discovering the cause is but one step in the process of correcting the problem. Every baby born with mental and/or physical disorder is tragic evidence of the need for further research and application of present knowledge.

So, if preventing handicapping conditions is the best hope of freedom and avoidance of dependency, early and intensive treatment is the second best hope.

A handicap can usually be made much less severe when treated in the early developmental period. When retardation is the result of sensory deprivation, research has indicated that early childhood stimulation and improved environment can often correct the condition.

For many children, it is already too late for such remedial intervention. But it is still possible to lessen the handicap considerably, and make these children less dependent than they would be if left untreated.

Many such research and treatment programs are going forward across the country. Results of the work strongly indicate the need for further positive action directed toward prevention of retardation and avoidance of dependency, so that more may benefit.

In order to hear from some of the people who are directly involved in these fields, PCMR held a Regional Forum in the Fall of 1973 at Kansas City, Missouri, with participants from Kansas, Missouri, Iowa and Nebraska. Other Forums are planned for the future.

The material in the next few pages is based on relevant, selected presentations made at the Forum. They start at the beginning of the chronology of prevention, with research on reproductive biology. They then move on to attempts to prevent disorders in high-risk pregnancies; through an early intervention program for infants and young children and their parents; and, finally, to an intensive, short-term program for severely handicapped children to prevent their long-term institutionalization.

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"The entire potential . . . in one cell."

"There is a moment in time when the entire potential of the individual is in one cell, a single microscopic cell invisible to the human eye," said Dr. John Spaulding in the opening words of his presentation at the PCMR Forum.

Dr. Spaulding, Director of the Children's Rehabilitation Center at the University of Kansas Medical Center, reviewed the Center's research into various stages of prenatal growth. In every stage of pregnancy, he explained, a number of events must occur in sequence in order to produce a healthy child.

First, researchers at the Medical Center are exploring the relationship of hormone levels to ovarian function in order to learn how conception is enabled to take place.

Then, to determine the elements that affect the survival very early in pregnancy, they are studying tissue implanted in the mouse uterus.

"A severe disruption at this very early stage would lead to death," said Dr. Spaulding, "but a less severe one may still distort the entire growth and development of that individual from there on."

The Medical Center is also investigating placental transfer in goats, with exactly dated pregnancies. They are especially looking into placental transfer of various significant drugs, to determine the effect of the drug on the goat fetus, and the dosage relationship.

Dr. Spaulding also discussed the Medical Center's fetal diagnostic studies, using the technique of amniocentesis, to draw fluid from the embryonic sac. [Many university medical centers and some other large medical centers are now offering amniocentesis and prenatal diagnosis to families.] He stressed the necessity for an experienced obstetrician to perform the amniocentesis; the need for a competent lab to do the chromosome, or biochemical, studies; and an expert in genetic counseling to interpret lab results and to offer a prognosis if the individual is diagnosed as affected.

What, for example, will it mean in the life of the person if he is found to have Down's syndrome?

"Counseling," he said, "has to be connected with some way of taking action. If the pregnancy is to be terminated, an expert obstetrician is

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needed. If the pregnancy is to be continued, there must be follow-up programs."

In the area of neonatal physiology, he described tests being done on newborn infants that may indicate whether or not the child can hear. Earphones are placed on the baby, and a pacifier put in his mouth. The pacifier is connected to sophisticated recording devices. The researchers then induce the child to suck, and feed sound into the earphones—a mixture of classical and folk music. The infants can be conditioned to suck for longer and longer periods because they seem to like to hear the music and "they will work (suck) for it."

When they reverse the process, said Dr. Spaulding, and turn off the music as soon as the child sucks, he will then suck less and less and less—indicating, it would seem, that he can hear.

"When this test is done in the incubator, it has shown that the background noise in there is deafening. The inside of an incubator is a loud, noisy, dripping, roaring place. One questions whether that's very good for the nerves of the infant."

John Spaulding, M.D.

"The most attractive isolette ever made."

From five to twenty percent of all women who are pregnant will have an infant who is at some degree of risk, Dr. Gerard Van Leeuwen told the PCMR Forum. The range is related to the socio-economic structure of the area.

The six major causes of death or brain damage in babies, he said, are low birthweight, maternal diabetes, maternal toxemia, blood incompatibility, congenital malformations, and complications of pregnancy.

Dr. Van Leeuwen, who is Professor and Chairman of Pediatrics at the College of Medicine, University of Nebraska at Omaha, is a "practitioner of newborn medicine," a specialty that requires at least two additional years of training after pediatric residency.

In small communities, he reported, there is usually one doctor who delivers the mother, and if the mother has difficulty, this means there is no one there to take care of the baby. Therefore, Dr. Van Leeuwen and his team emphasize the importance of a second, trained person to resuscitate the baby.

He pointed out a few of the dangers at the time of delivery. Too much oxygen may cause blindness and lung damage; not enough may cause brain damage. Letting a baby get cold also may produce brain damage, he said.

Other causes of neonatal brain damage that he cited are low blood sugar, infection, and jaundice when it is severe enough for the bilirubin (which causes jaundice) to reach a certain level in the blood and enter the brain—one of the common causes of cerebral palsy.

One of the methods Dr. Van Leeuwen and his team use to prevent disability in high-risk newborns is a transport isolette which carries its own oxygen and can be used in a car or airplane. This equipment plus a box of medication and supplies are all that is needed to provide total care of the infant from the moment he is picked up at the emergency entrance of the referring hospital or the home, and brought to the newborn intensive care unit at the University of Nebraska Hospital.

> *"Those of us who are in the business of preventing mental retardation and developmental disabilities and those who are treating the problem often don't realize that we're in the same business."*

"Probably the best way to move the infant, however," Dr. Van Leeuwen said, "is inside the uterus."

He called the uterus "the most attractive transport isolette ever made. It hardly ever gets dropped. It never runs out of electricity, and it has a number of other advantages. It keeps the baby oxygenated and warm."

He reported that during the first six months of 1973, 75 mothers were transferred to the hospital; in 1963 none were. The team transported four babies in 1968. During 1973 they transported 250 babies.

By taking these extra measures, they initially believed they could reduce the number of deaths by half, and prevent some of the brain damage and disability. The results, however, have exceeded the expectations.

Dr. Van Leeuwen reported that a 1949 to '53 long-term survival study in Colorado on 91 babies who weighed four pounds or less at birth indicated that 66 percent had handicaps. One-third of these handicapped children were severely mentally retarded or had cerebral palsy or were blind.

In the Nebraska program, he said, serious handicaps are down to about 6 percent of the survivors. The survival rate has doubled.

In 1973, he said, at least 75 percent of the infants under four pounds in their program appeared to be mentally normal and have minimal developmental disabilities—despite the fact that these were all high-risk infants.

Dr. Van Leeuwen added that there is still a possibility that a number of these children may have minor disabilities that would not be discovered until they may have learning problems at school.

Cost for the intensive medical care of a high-risk newborn infant is often $5,000, he said, and frequently reaches $20,000, paid for in a number of ways—insurance, parents, the State. State dollars have not been used for air transport, however. "This is a small price to pay for a normal brain and a normal body," he concluded.

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Goals for each child

The purpose of the Infant Development Center, Lake Quivira, Kansas City, Kansas, is to provide developmental education immediately upon identification of high-risk or suspected atypical infants, and to provide supportive and informative counseling for the family. The program was described to the PCMR Forum by the Center's director, Lee Ann Britain.

"The impact of the birth of a handicapped child on the family is a devastating experience."

"We like to get to the mother right away and give her emotional support, and let her meet other mothers in similar circumstances."

"The mother, or whoever has the primary care of the child, is the developmental educator, trained by the Center's staff."

"Highly individualized goals are set for each child by the staff in the development of gross motor, fine motor, adaptive, language, and personal-social skills."

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"If we don't do anything for this child now . . ."

To prevent long-term admissions, Woodward State Hospital-School, Woodward, Iowa, has started a short-term intensive treatment unit and respite care program for children from birth to 12 years of age. Dr. S. B. Hussain, Clinical Director, reported in his PCMR Forum presentation.

The expressed purpose is to assist parents in the home management of their child and possibly avoid the need to place him in an institution.

"The difficulty of rearing a retarded child in the home can be reduced through early intervention in behavior management and special therapy techniques," Dr. Hussain said. "When we see a child in the Diagnostic Clinic with serious problems, we know that if we don't do anything for this child now, he'll be a long-term institutionalized person."

He cited examples of children with "legs like scissors," children who are hyperactive, or not toilet trained. The schools can't serve these children, he said. So the clinic admits them for two or three months, has orthopedic surgery done, or toilet trains the child, or provides behavior modification. Then they train the parents in physical therapy or behavioral techniques, or whatever is needed to continue the treatment. The child can then live at home and go to school.

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The teachers are also advised on the child's needs.

Dr. Hussain told of an 8-year old child with Down's syndrome, who was in the short-term respite care program. At the time of admission, she had no independent self-help skills. Three months later when she was discharged, she was able to feed and dress herself and meet her toileting needs independently.

All of the children given the intensive, short-term treatment at the unit are back in their communities and progressing well, according to Dr. Hussain. Left alone, he said, these are the sure candidates for long-term institutionalization.

PCMR BELIEVES THAT:

Mentally retarded people are capable of continuing development

The fact that people who are retarded can develop with intensive care and under favorable environmental conditions has been effectively demonstrated. A hostile environment, however, can block progress even when the internal barriers to growth and development have been removed.

In order to promote a more receptive environment in which persons who are retarded can develop in the freest possible way, with the opportunity to exercise the same rights as other citizens, in 1973 PCMR:

Held the first national conference on The Mentally Retarded Citizen and the Law to help educate the legal profession and the public to human and legal rights to which retarded persons are entitled;

Assisted in the preparation of two publications resulting from the legal rights conference: One a professional legal reference document; the other an action-oriented report for a general audience;

Promoted acceptance of retarded citizens in communities, and emphasized their right to choose a place of residence, through radio and TV public service announcements, distributed nationwide;

Launched a joint effort with architects to improve building codes, zoning regulations, and other barriers to community living;

Contracted for updating the PCMR publication that was so influential in promoting the normalization principle, *Changing Patterns in Residential Services for the Mentally Retarded;*

Directed preparation of a monograph on planning community services for mentally retarded persons living away from home;

Cooperated with the Law Enforcement Assistance Administration in a Southeastern Regional Conference on the Mentally Retarded Citizen and the Criminal Justice System;

Joined with the American Association on Mental Deficiency in a regional conference on legal rights in Morgantown, W.Va.;

Participated in a Conference on Services for the Retarded Adult held in Santa Barbara, California;

Published a professional paper on *Experimental Studies of Memory in the Mentally Retarded*, which explores the learning process and possibilities for accelerating it;

Took leadership in exploring the effects of the energy shortage with several private and governmental organizations serving retarded persons, and designed a survey on the impact of cuts in heating fuels and gasoline on mental retardation programs;

Proposed to the Secretary of DHEW ways and means to meet the urgent need to develop executive manpower for mental retardation and other human services programs.

PCMR BELIEVES THAT:

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Corrective measures introduced in early childhood can reduce the severity of the handicap and sometimes reverse its course

Research data strongly indicate that the first five years of life are crucial in the development of each individual. This is especially true of children born with a handicap. If problems are detected and treated in these early years, the damage can often be considerably lessened. In some cases, the course of the condition can be reversed.

To encourage early detection and correction of handicaps, and to publicize the most recent advances, in 1973 PCMR:

Published a definitive monograph on *Screening and Assessment of Young Children at Developmental Risk*, an extension of the theme of a 1972 PCMR conference on the subject. (Available only from Superintendent of Documents, GPO, Washington, D.C. 20402. $2.40. SN 4000-00294.)

Completed plans to cosponsor a Conference on Infancy and Early Childhood Education, with the Association for Childhood Education International, and several other agencies, to be held in the spring of 1974;

Published a professional paper on *Malnutrition, Learning, and Intelligence*, summarizing research data on the effects of malnutrition on brain growth and learning ability.

Dr. Henry Cobb lends a hand with phonics.

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Committee members actively participated in the programs at the Kansas Center for Mental Retardation and Human Development at the University of Kansas in Lawrence, during a visit in conjunction with a Regional Forum in 1973.

Nan Ulle beating the drums in music therapy.

Ralph Ferrara gives a friend a head start.

Kenneth Robinson astonishes a friend with his block-building skills.

William Robertson teaches reading readiness.

PCMR BELIEVES THAT:

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Prenatal and neonatal biomedical intervention can prevent many forms of mental retardation and related handicaps

Reproduction is an intricate process. One extra chromosome in the genetic inheritance, a virus contracted by the mother at a certain time in the pregnancy, an untreated infection, these and many other factors can cause the child to be damaged.

To stimulate advances in the techniques of prevention of mental retardation, and to inform the public on preventive measures, in 1973 PCMR:

Brought together a group of leading geneticists to review the state of the art and to identify methods of meeting needs;

Produced a series of radio spot announcements in English and Spanish to inform prospective mothers on how to increase their chances of having healthy children.

Marianna Beach offers a reward for improved behavior.

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There was other Committee business in 1973 that touched on each of these areas. Members and the executive director addressed numerous groups and attended conferences in this country, Europe, England and Latin America. They testified before committees; they were interviewed on radio, TV, and for newspapers and magazines.

Some 1973 Committee activities that touched on all areas in the mental retardation field included:

A Mid-Atlantic Leadership Training Institute held in Richmond, Virginia, which brought together people from Pennsylvania, Delaware, Maryland, Virginia, West Virginia, and the District of Columbia, to report and discuss progress and problems in mental retardation in those States;

A Midwest Regional Forum held in Kansas City, Missouri, at which representatives of Kansas, Iowa, Missouri, and Nebraska gave presentations and demonstrations of their programs to aid persons who are mentally retarded and to prevent handicapping conditions;

Advance meetings to plan for a major Inter-American Conference on Mental Retardation to be held in 1975, in which PCMR will participate.

Louise Ravenel and PCMR Executive Director Fred Krause get involved.

Dr. Cecil Jacobson observing a pre-school class.

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Executive Director

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John D. Thompson, M.D.

Thomas A. Tucker

The President's Committee wishes to express its sincere appreciation for the gift of time and talent by Andrew J. Molnar, Vice President and Art Director of Ceco Publishing Co., Troy, Michigan.

The Committee also wishes to thank the numerous individuals in the following facilities who contributed many of the photographs, much of the information and most of the inspiration for this report.

The National Children's Center, Washington, D.C.
The Occupational Training Center, Washington, D.C.
Sunland, Tallahassee, Florida
Sunland, Marianna, Florida
Montgomery County (Maryland) Association for Retarded Citizens
University of Kansas Medical Center, Kansas City
College of Medicine, University of Nebraska
Infant Development Center, Kansas City, Kansas
Woodward State Hospital School, Woodward, Iowa
The Hospital for Sick Children, Washington, D.C.
Mental Retardation and Child Psychiatry Media Unit of the Neuropsychiatric Institute, University of California, Los Angeles
Illinois Braille and Sight Saving School, Jacksonville, Ill.

A FINAL WORD FROM THE EXPERTS

"Not everybody's the same."

In a completely spontaneous, frank discussion, a group of eight adolescents sat down together one evening in 1973 and talked about mental retardation. All had been in special education classes, all have grown up with the label "retarded."

Their conversation was video-taped at the Mental Retardation and Child Psychiatry Media Unit of the Neuropsychiatric Institute, University of California, Los Angeles. With UCLA's permission, these quotes were taken from portions of the discussion.

"I think when we were being born, Mother Nature made some mistake and it damaged part of the brain and something didn't turn out right, and it held us back."

"A different thing happened to each of us."

"Not everybody's the same."

"It depends on the person—on how much they have on the ball."

"Like my cousin Russell. All the time, 'I can't do this,' and 'I can't do that.' I tell him, 'Russell, yes you can. You can, too' "

"Like me. I *try* because I want to get ahead. In 9th grade I got out of Special."

"To accomplish something takes you twice the effort. . . . To get a C, I would have to work like an A student."

"Once I sat down and cried because I was in a gym class and I had a problem. Everybody threw rocks at me and ran up and hit me and I turned around and hit them back. The teacher walked around laughing and showing this roll book. It said F F F F. Eventually I got out of this class. . . . I was put in a special gym class where some people had problems and where people were more grown up. Later on, I went to a doctor for some help, and I found out what the problem was: . . . Very poor visual perception. That was the thing that was holding me back."

"I realize that I'm 21 and I . . . want to have a car and . . . all these things. And yet I get uptight about it with myself . . . I'm my own worst enemy. I just told the guys the other day, 'There's only one person in this apartment that I don't get along with: Me!' "

"The emotion does figure in it. It's reversed. Because you want to do things but you know you can't. And you keep on fighting it and you keep on pushing harder and harder to get there faster and faster."

"We'll have problems with holding certain types of jobs. Like I know I'll probably never make it to be an engineer. . . . The question is still open."

"I wanted to be a social worker. But it would take me 14 or 15 years to do it. So, realistically. . . ."

"You have to face the fact that that's one thing you can't do."

"You know you are [retarded], and everybody calls you it. But you don't want to say it. You know you are within. It chops you down."

"It's more the way it is said. It's not just that word. It could be any word, really."

"I think parents should tell the kid what is wrong with them. They're going to have to find out sooner or later."

"Sooner is better than later."

"You can't hide it from the kid because he's going to find out eventually anyway that there's something wrong—like I did."

"You gotta evaluate the youngster on an individual basis. Not compare one to another, like a tennis match."

"But discipline should be the same for all children."

"Even though they* may have learning problems, they're human beings just like *everybody* else, and they deserve basically the same treatment as any other human being."

"The object is to motivate them to try harder . . . and to encourage them."

"You never stop learning. You learn things every day of your life."

"Let the kid go out and make his own mistakes and learn from them."

"They'll grow out of some [of the mental retardation], but if the mother protects them, they'll never grow out of it."

"They'll go into a shell. A live vegetable."

"You aren't going to learn anything if somebody's doing something for you all of the time."

"My mother will always see me as a baby, no matter how old I get."

* Some of the speakers use "they" in referring to other retarded persons.

"You have to have the experience of knowing how to live when Mom and Dad aren't around. Because one day they die, too."

"And later on in life, nobody's going to teach you how to be independent and what to do."

"There comes a point when you have to let go . . . when you've got to get them their freedom. Slowly, but surely, they'll get their independence."

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
WASHINGTON, D.C. 20201

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DHEW Publication No. (OHD) 74-21001